

Crescent Cove To Open: A Special Resource for Children and Families

By Ted Bowman and Dannel Shu

Background from Ted

For over twenty years, I have had the privilege of working annually in England, Scotland and Ireland. Early on, I became aware of and later began to do workshops in what there are called children's hospices. There are over fifty of these home-like facilities in England alone. About ten years ago, I began meeting with a local woman, Katie Lindenfeser, who had a dream that such a facility might be built or found in Minnesota. For her that dream grew out of work she did as a music therapist at Children's Hospital and after traveling in Australia and England. She persisted in exploring the dream and now, her dream, and mine, will become reality.

In November 2017, Crescent Cove will open its doors in Brooklyn Center as only the third children's respite and hospice home in the United States, and the first located in the Midwest.

Crescent Cove's mission is to provide care and support to kids and young adults with a shortened life expectancy and the families that love them. In addition to the home where kids and young adults can stay for respite (short periods) and as a sacred place for end-of-life care,

Crescent Cove will offer a unique suite of programs and integrative therapies designed specifically and exclusively for these vulnerable children, all at no cost to the families.

In metro areas around the U.S., there are over 4700 hospice homes for adults, and only two currently exist for kids and their unique needs. Crescent Cove aims to serve families in Minnesota and the Midwest in their most precious hours, allowing every day to be a chance to experience joy and comfort.

A Mom's Story from Dannel

It was Christmas time and we were anticipating the birth of our first child. My pregnancy had gone beautifully and days before Christmas he was born; born without a heartbeat or breath. He did not move or cry. Our son, Levi, had been born with severe brain damage and a host of reverberating medical complexities. His ambiguous diagnosis thrust us into unfamiliar terrain as death hovered.

My husband and I chose to fully embrace each precious moment with Levi, placing one foot firmly in the stark realities of his prognosis and another in the flight of hope with faith. Three weeks later Levi "graduated" the NICU. We arrived home with the support of palliative care, establishing an in-home ICU and clueless about what was to come. It wasn't until Levi survived his first pneumonia at 10 months that we paused to consider his life might be more than a few weeks. Seven years, two months after his birth, Levi lifted off to heaven.

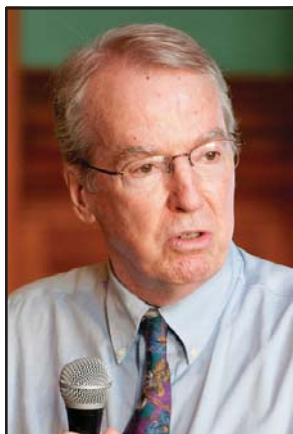
In Levi's lifetime we were fortunate to have hospital-based palliative care and the emerging services of Crescent Cove. (Even before the site opens in November, Crescent Cove has been offering some services to families). This combination has not been there for most families. The opening of Crescent Cove's residential home is profound and significant for families whose child has a life-limiting condition. Here are two key reasons why I support Crescent Cove.

A Life-Loving Ethos

At Crescent Cove families will experience joy-bringers who cherish life, respect the immense challenges a family like ours faces, and work to relieve suffering. Every element is being designed to maximize a child's quality of life: sacred spaces, nurturing staff, creative services, meaningful resources, and supportive relationships. The ethos of the home recognizes the spiritual nature of living as a family with a child with a limited life. Children and parents can depart refreshed, supported, embracing cherished memories, and a desire to return. This will be so after respite and end-of-life experiences.

We experienced the gift of this life-loving ethos through sessions with a music therapist, massage therapy, home-cooked meals delivered, surprise events and gifts, couples counseling, and mini-respite breaks. Every person we met was a joy-bringer who lightened our load. Even as we faced Levi's approaching death, Crescent Cove was helping us cherish each precious moment while supporting our transition as a family.

Being in this ethos will shift a family's perspective of uncertainty,



Ted Bowman



Dannel Shu

Crescent Cove continued on page 7

Crescent Cove continued from page 6

encouraging parents like us to experience all of the wonder and beauty of childhood while balancing the difficult realities we face. It will transform what it means to parent a child with a shortened life and journey further with siblings. This life-loving ethos brings death into perspective as a natural aspect of life, even for a child with a shortened life.

A Home Away from Home

It is near impossible to find a place that mirrors home, particularly for children with life-limiting conditions. A place of safety, refuge, understanding, joy, launching, and support. As a result families can be isolated which can compromise their capacity for resilience. Crescent Cove's respite care will allow children to have meaningful experiences as their family decompresses and recharges. Their end-of-life care will allow families to purposefully honor and celebrate their child's passing in an environment of "home."

This place of "home" is desperately needed by families. During Levi's life we would have benefitted from having a familiar place where we could entrust his care to allow for a time of respite. A place where his time there would be fun and memorable for him. A place where Levi could have made friends. A place outside of our home to journey through his end-of-life.

This sensation of "coming home" at Crescent Cove will be a critical way of building resilience and decreasing spiritual pain. Families will have the opportunity to experience and expand their own values with greater levity. Crescent Cove will be a place children and siblings request to come home to again and again.

Putting Crescent Cove in Context, from Ted

Many that heard of Crescent Cove have raised important questions:

- ◆ How will this be different from children's hospitals throughout Minnesota?
- ◆ If this is not a fully residential site, how does what you do overlap with quality home-care?

To be sure, Minnesota has wonderful children's hospital services. Crescent Cove will complement those services, not be in competition with or undermine what they do well. Indeed, children served by Crescent Cove may need to go to an acute care facility at times. Levi, Dannell's son, did require some emergency care during his seven years and was in the PICU once at age three, his only time there except at birth.

Crescent Cove will collaborate with the various hospitals serving children by accepting referrals and by sending children to such hospitals when required. Even so, children like Levi can benefit from receiving medical

and complimentary care in a home-like facility with staff they know, not in an acute care hospital no matter how friendly it is.

Crescent Cove will also build and strengthen ties with a variety of home-care and palliative care volunteers and professionals. When there is more dialogue and collaboration between providers, families benefit. English colleagues report to me that both home care providers and staff of children's hospices have been enriched by mutual care. When done well, parents report less comparisons and more continuity of care.

It is our hope that MCDES members and friends will be supportive of Crescent Cove in the months and years ahead.

Editor's Note: Ted Bowman, long-time MCDES member, is a grief and family educator based in St. Paul. He serves on the Clinical Advisory Committee for Crescent Cove. Dannell Shu is a parent advocate who blogs about the family experience within pediatric palliative care, www.MamaShu.org. She is a member of the Pediatric Palliative Care Coalition of Minnesota, the Palliative Care Coalition of Minnesota, and UMMCH & Fairview's Home Care and Hospice Pediatric Advanced and Complex Care Team Advisory Committee. If you have questions after reading this article, visit the Crescent Cove website, www.crescentcove.org, or contact Ted Bowman, tedbowman71@gmail.com.



Crescent Cove — respite and hospice home

Even as we faced Levi's approaching death, Crescent Cove was helping us cherish each precious moment while supporting our transition as a family.

~ Dannell Shu